





# Preparing Graduate Nursing Students to Ensure Quality Palliative Care for the Seriously III & Their Families

#### Introduction

Master's and doctorally-prepared nurses play a critical role in the care of more than 117 million Americans, from pediatric to geriatric patients, who are living with serious illness (CDC, 2017). As the number of older adults is expected to double over the next 25 years, specialty palliative care practitioners will not be able to meet the future demand. Thus, it is critical that graduate nursing students be prepared to address this gap by becoming educated in primary palliative care. These nurse leaders must be skilled in primary palliative care in order to succeed in advanced nursing practice roles in clinical practice, administration, or academia. This document is a timely and essential statement regarding nursing education to lead change, design and implement innovative models of primary palliative care delivery, build and lead interprofessional teams, and evaluate the outcomes of safe, evidence-based, and effective care.

#### What is Palliative Care?

"Beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families, and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care providers" (NCP, 2018).

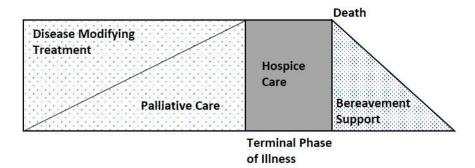
In addition, palliative care is:

- Appropriate at any stage of illness and beneficial when provided in tandem with treatments of curative or life-prolonging intent
- Provided over time, based on needs and not prognosis
- Offered in all care settings (in the community, acute care, clinics, cancer centers, dialysis units, homecare agencies, long-term care/skilled nursing facilities, hospices, telehealth, etc.)
- Focused on what is important to the patient, family/caregiver(s), assessing their goals of care and preferences, and determining how to achieve them (NCP, 2018).

The 2014 Institute of Medicine (IOM) report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, affirmed that "everyone should have access to palliative care" (IOM, 2014). As the largest group of healthcare professionals in the United States (3.6 million strong), nurses, especially those who are master's/doctorally-prepared, must

be educated to provide holistic, person-centered care; to identify, respect, and advocate for patient choices regarding goals of care; and to promote access to and provision of palliative care. Thus, the American Nurses Association (ANA) and the Hospice and Palliative Nurses Association (HPNA) have concluded that "seriously ill and injured patients, families, and communities should receive quality palliative care in all care settings. This is achieved by the delivery of primary palliative care provided by *every* nurse, regardless of setting (ANA & HPNA, 2017).

The diagram below delineates the continuum for palliative and hospice care as the disease progresses and the patient enters into the terminal phase of illness (NQF, 2006). Palliative care is integrated from the time of diagnosis of a serious illness and continues throughout active treatment, the terminal phase, and bereavement.



## Continuum of Care

#### The Need

Nurses educated at the master's and doctoral levels are in great demand. Americans are living longer, the number of people who are seriously ill is increasing, and this growing population needs nurses educated at higher levels to provide competent and compassionate care. According to the Centers for Disease Control and Prevention (CDC), 1 in 2 adults in the US has a chronic illness, and 1 in 4 adults has 2 or more diseases (CDC, 2018). Care is often complex and fragmented. Advanced nursing practice providers oversee the care of seriously ill patients and coordinate their care from multiple providers. These patients have numerous comorbidities, and their complex care can be overwhelming in the midst of healthcare system challenges. Often, patients and families experience needless suffering.

Many aspects of care can be improved by educating nurses at their highest level of practice (IOM, 2011; IOM, 2014). For example, communication between the healthcare professionals and patients/families is often poor. ANP providers serve as key advocates for effective communication and informed decision making (IOM, 2011; IOM, 2014). Few patients are assessed "holistically"; ANP providers can provide assessments addressing physical, psychological, social, and spiritual needs. Many seriously ill patients enter the healthcare system without advance care planning conversations. Goals of care are infrequently discussed

between the healthcare team and patients/families, resulting in burdens of treatment/care outweighing the benefits. ANP providers are in a strong position to initiate and lead these conversations. Often patients access expert pain and symptom management or palliative care during their last few days of life, rather than earlier on in the disease trajectory. Also, there are too few palliative care specialists and limited primary palliative care knowledge among other clinicians who care for those with serious advanced illness (IOM, 2014). ANP providers educated in primary palliative care can fill that gap.

There is growing evidence regarding the tremendous need for all master's and doctorallyprepared nurses to be educated and provide primary palliative care.

- By 2030, The Association of American Medical Colleges (AAMC) estimates the demand for physicians will grow faster than the supply—a projected shortfall between 40,800 – 104,900 physicians (Dall et al., 2017). Yet the demand for primary care will continue to increase as the 76 million baby boomers age into the Medicare program, requiring excellent assessment and management for complex and multiple comorbidities (Buerhaus, 2018). With a decrease of the number of physicians entering primary care and as the US population ages, master's and doctorallyprepared nurses will be needed on the forefront to assess and care for many of these patients.
- As the population in the US continues to grow, demographics are rapidly changing, and people are living longer with serious illnesses such as cardiovascular and Alzheimer's diseases. The growing cancer population requires palliative care from diagnosis through treatment, recurrence, survivorship, or at the end of life and family bereavement (Ferrell et al., 2016 & ONS, 2014). A record number of new cancer diagnoses, survivors, and cancer-related deaths will require more nurses at the graduate level to be prepared to collaborate with the interprofessional oncology team to meet patient and family needs.

#### Background of the G-CARES Document

The *Graduate Competencies And Recommendations for Educating Nursing Students (G-CARES) document* builds on the American Association of Colleges of Nursing (AACN) *Competencies And Recommendations for Educating Undergraduate Nursing Students (CARES) document. CARES* identifies the 17 essential competencies undergraduate nursing students need to have completed by the end of their pre-licensure education. In addition, the AACN Master's and Doctor of Nursing Practice (DNP) Essentials (2011 and 2006, respectively), The National *Consensus Project Clinical Practice Guidelines for Quality Palliative Care, 4<sup>th</sup> Edition (2018),* American Nurses Association (ANA) and Hospice and Palliative Nurses Association (HPNA) <u>Call for Action: Nurses Lead and Transform Palliative Care</u> (2017), and the Institute of Medicine report, *Dying in America Improving Quality and Honoring Individual Preferences Near the End of Life* (2014), provide a foundation for the development of these graduate competencies. When embedded within Master's and DNP curricula, these competencies will prepare graduates to lead clinical practice, healthcare systems, quality improvement, and academic changes needed to advance the access of primary palliative care to all patients with serious illness.

#### Primary Palliative Care Competencies for Master's and DNP Nursing Students: (G-CARES) <u>G</u>raduate Competencies <u>And Recommendations for <u>E</u>ducating Nursing <u>S</u>tudents</u>

The *G-CARES* document contains two sets of competencies. The first eight primary palliative care competencies are expected of all graduate nursing students, including master's, (i.e. advanced practice registered nurses (APRN), Clinical Nurse Leaders (CNL), nurses in education, administration, informatics, and public health, etc.) and Doctor of Nursing Practice (DNP) students who will be **directly or indirectly** providing primary palliative care for seriously ill patients and their families, from infants and children through geriatric populations, and across the illness trajectory. The second five primary palliative care competencies are expected of graduate nursing students who will be providing **direct** primary palliative care across any clinical, community, or technology-mediated (telehealth) setting. Appendix I describes the alignment of the *G-CARES* Competencies with the AACN Master's and DNP Essentials and the 4<sup>th</sup> edition of the *NCP Guidelines for Quality Palliative Care*.

Primary Palliative Care Competencies for All Master's and DNP Nursing Students:

- 1. Articulate the value of palliative care as a basic human right at a local, national, and global level.
- 2. Advocate for access to palliative care and hospice services as standard practice in all clinical, community, and technology-mediated (telehealth) settings.
- 3. Contribute to creating, critiquing, translating, and evaluating the evidence-base for primary palliative care from nursing science, ethics, biophysical, psychological, sociological, spiritual, and organizational sciences into clinical practice, administration, and education.
- 4. Identify the dynamic changes in population demographics, healthcare economics, service delivery, caregiving demands, and financial impact of serious illness on patients, families, professionals, and healthcare systems to develop models of interprofessional primary palliative care that improve patient/family, professional, and system outcomes.
- 5. Promote social justice, equity, and equality for the seriously ill, one of the nation's most vulnerable populations, within clinical and educational settings, professional organizations, and state and national legislatures.
- 6. Communicate and collaborate with organizational and policy leaders to eliminate health disparities and financial and regulatory barriers related to palliative care.
- 7. Educate consumers, stakeholders, community leaders, policy makers, and healthcare providers regarding patient/family, professional, and system outcomes related to the provision of primary palliative care.
- 8. Role-model resiliency and sustainability to patients/families and interprofessional healthcare providers, demonstrating strategies for coping with suffering, loss, and moral distress associated with serious illness.

Primary Palliative Care Competencies for All Master's and DNP Nursing Students Who Will be Providing <u>Direct</u> Patient Care:

- 1. Perform a focused assessment of the physical, psychological, social, and spiritual needs of patients and families, addressing all dimensions of quality of life in collaboration with other interprofessional providers.
- 2. Manage common pain and symptoms associated with serious illness, recognizing when to access specialty palliative care services, if available, for complex issues.
- 3. Demonstrate communication expertise in primary palliative care skills, in particular sharing difficult news, discussing advance care planning and completing advance directives, in facilitating/leading family and interprofessional team meetings, and transitioning to hospice care when appropriate.
- 4. Apply evidence-based and ethical/legal principles in prescribing and de-prescribing medications, ordering diagnostic tests and recommending treatments, reflective of patient and family goals of care.
- 5. Collaborate with the seriously ill patient, family, and interprofessional healthcare team from the time of diagnosis, to develop, manage, and coordinate a culturally-sensitive, patient-centered, family-focused, and evidence-based plan of care across care transitions, through bereavement, and through the appropriate use of technology.

#### **Key Definitions**

**Caregiver:** The term caregiver includes family or friends, or others, either paid or unpaid (NCP, 2018).

**Direct care provided by ANPs:** Characterized by the use of holistic care, formation of therapeutic partnerships with patients, provision of expert clinical performance, use of reflective practice, practice guided by evidence, and use of diverse approaches to both health and illness management (Lusk et al., 2018).

**Family**: In palliative care, family is always defined by the patient and can include the family of origin (parents, siblings, children), family of choice (spouse, friends, neighbors), and caregivers (NCP, 2018).

**Hospice:** "Hospice is a specific type of palliative care provided to individuals with a life expectancy measured in months, not years. Hospice teams provide patients and families with expert medical care, emotional, and spiritual support, focusing on improving patient and family quality of life" (NCP, 2018).

**Indirect care:** "Indirect care refers to nursing decisions, actions, or interventions that are provided through or on behalf of individuals, families, or groups. These decisions or interventions create the conditions under which nursing care or self-care may occur. Nurses might use administrative decisions, population or aggregate health planning, or policy development to affect health outcomes in this way. Nurses who function in administrative capacities are responsible for direct care provided by other nurses. Their administrative decisions create the conditions under which direct care is provided. Public health nurses organize care for populations or aggregates to create the conditions under which care and improved health outcomes are more likely. Health policies create broad scale conditions for delivery of nursing and health care" (AACN, 2015).

**Primary palliative care (also referred to as generalist palliative care)**: Palliative care that is delivered by healthcare professionals who are not palliative care specialists, such as primary care clinicians; physicians who are disease-oriented specialists (such as oncologists and cardiologists); advanced nursing practice providers and nurses, social workers, pharmacists, chaplains, and others who care for this population but are not certified in palliative care (IOM, 2014; NCP, 2018).

**Serious illness:** A health condition that has a high risk of mortality and negatively impacts a person's ability to function and/or quality of life OR causes excessive stress and strain on their caregiver (Kelley & Bollens-Lund, 2018).

**Specialty palliative care:** Care that is delivered by healthcare professionals who are palliative care specialists, such as physicians who are board certified in this specialty; palliative-certified

registered nurses and advanced practice registered nurses; and palliative care-certified social workers, pharmacists, and chaplains. (IOM, 2014; NCP, 2018)

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## **APPENDIX I**

## **Competencies for All Master's and DNP Nursing Students**

	Competency	Master's Essentials	DNP Essentials	NCP Guidelines
1.	Articulate the value of palliative care as a basic human right at a local, national, and global level.	VI; VIII; IX	V	1,8
2.	Advocate for the provision of palliative care and hospice services as standard practice in all clinical, community and technology-mediated (telehealth) settings.	II; VI; VIII	II-V	1,7,8
3.	Contribute to creating, translating, and evaluating the evidence-base for primary palliative care from nursing science, ethics, biophysical, psychological, sociological, spiritual, and organizational sciences into clinical practice, administration, and education.	I; IV; IX	I-VI	1-8
4.	Identify the dynamic changes in population demographics, healthcare economics, service delivery, caregiving demands, and financial impact of serious illness on patients, families, professionals, and healthcare systems to develop models of interprofessional primary palliative care that improve patient/family, professional, and systems outcomes.	II; III; IV; VII-XI	IV; V; VI	1,4,6

5.	Promote social justice, equity, and equality for the seriously ill, one of the nation's most vulnerable populations, within clinical and educational settings, professional organizations, and state and national legislatures.	V; VII; VIII	V	4,6
6.	Communicate and collaborate with organizational and policy leaders to eliminate health disparities and financial and regulatory barriers related to palliative care	V; VI; VII; VIII	II; IV-VI	1,4,6
7.	Educate consumers, stakeholders, community leaders, governmental officials, healthcare providers, and policy makers regarding patient/family, professional, and system outcomes related to the provision of primary palliative care.	VI; IX	II; IV-VI	1-8
8.	Role-model resiliency and sustainability to patients/families and professional caregivers, demonstrating strategies for coping with suffering, loss, and moral distress associated with serious illness.	VII; IX	VI	6,7,8

## **APPENDIX II**

## Competencies for All Master's and DNP Nursing Students Preparing for Direct Advanced Practice Nursing Care

1.	<b>Competency</b> Conduct a focused assessment of the physical, psychological, social, and spiritual needs of patients and families, addressing all dimensions of quality of life.	Masters' Essentials I; VIII; IX	DNP Essentials I-IV	NCP Guidelines 2,3,4,5
2.	Manage uncomplicated pain and symptoms associated with serious illness, recognizing when to access specialty palliative care services, if available, for complex issues.	I; VIII, IX	I; III-V	2,5,7
3.	Demonstrate communication expertise in primary palliative care skills, in particular sharing difficult news, discussing advance care planning, and in facilitating/leading family and interprofessional team meetings.	IV-V; IX	IV; VI	1,4,5
4.	Demonstrate knowledge and skill in providing culturally-inclusive primary palliative care throughout the illness trajectory and bereavement.	I; VIII	II; V-VI	5,6,8
5.	Apply evidence-based and ethical/legal principles in prescribing and de-prescribing medications, ordering diagnostic tests, and recommending treatments, reflective of patient and family goals of care.	I; III; VIII-IX	I; III; VI	2,3,8

6. Collaborate with the seriously ill patient, family, and interprofessional healthcare team from the time of diagnosis, to develop, manage, and coordinate a patient-centered, family-focused, and evidence-based plan of care across care transitions, through bereavement.	I-III; VII-VIII	I; III-VI	1-8
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## Appendix III

## A Critical Resource for Graduate Nursing Faculty: Online Palliative Nursing Education Curriculum

Integrating additional graduate level nursing content into an already saturated curriculum can be challenging. Faculty who have not taught palliative care concepts before may feel unprepared to introduce new competencies and content into their courses. In order to meet the needs of both nursing faculty and students, we are developing a series of six online modules that address all components of palliative care as recommended by the *National Consensus Project Guidelines for Quality Palliative Care* (4<sup>th</sup> ed.) and will provide a mechanism to meet the competencies in this document. The APRN and DNP modules developed by the End-of-Life Nursing Education Consortium will be the foundation for this online curriculum. The six modules can be used in face-to-face classroom education, online education, or as a combination of both face-to-face and online, depending on faculty preference.

Topics that will be covered are:

- 1. Introduction to Palliative Care
- 2. Communication
- 3. Pain Assessment & Management
- 4. Common Symptoms: Assessment & Management
- 5. Final Hours of Life
- 6. Palliative Care Leadership

Ethical and legal principles as well as psychosocial, spiritual, and cultural considerations will be woven throughout the six modules. Each module will include objectives, interactive slide content, video vignettes role modeling primary palliative care skills, case studies, supplemental materials and online resources and references.

A five-question quiz will be added at the end of each module. Successful mastery (80% or higher) of each of the six modules is required to be awarded a certificate of completion of the ELNEC-Graduate education.

#### **Recognition:**

It is with gratitude that the End-of-Life Nursing Education Consortium (ELNEC) recognize the Cambia Health Foundation for their financial support in developing <u>Graduate Competencies And</u> <u>Recommendations for Educating Nursing Students (G-CARES)</u>.

In addition, the following nursing faculty, organizational leaders, and clinicians have assisted in developing this document:

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Endorsed by the American Association of Colleges of Nursing Board of Directors, January, 2019

Since its inception in 2000, the End-of-Life Nursing Education Consortium (ELNEC) has been a partnership between the American Association of Colleges of Nursing (AACN), Washington, DC and the City of Hope, Duarte, CA. <u>www.aacnnursing.org/ELNEC</u>